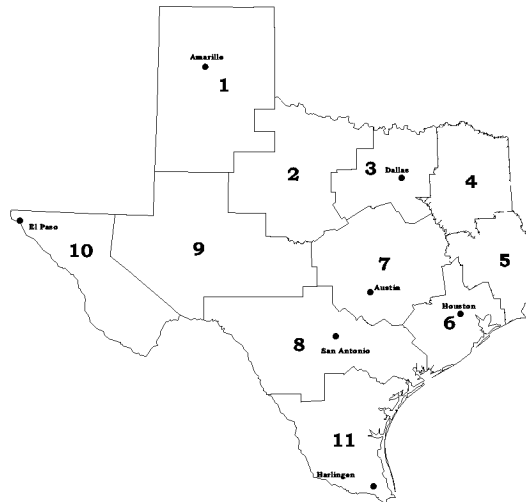


Methods

Scope of this Report

This report presents information on selected birth defects among deliveries during 1999 and 2000 to women who were residents of Texas. During 1999 and 2000, the Texas Birth Defects Registry covered all eleven regions of the state for the entire year.



This report includes information in the Texas Birth Defects Registry as of April 30, 2003.

Case Definition

To be included as a case in the Texas Birth Defects Registry, all of the following criteria must be met:

- The mother's residence at the time of delivery must be in an area covered by the registry.
- The infant or fetus must have a structural birth defect or developmental disability monitored by the registry.
- The defect must be diagnosed prenatally or within one year after delivery. This is extended to six years of age for special cases, currently only for fetal alcohol syndrome.

The current case definition includes all pregnancy outcomes (live births, spontaneous fetal deaths, and induced pregnancy terminations) at all lengths of gestation. This case definition differs in two important ways from the case definition used in some earlier data reports. For this reason caution should be exercised when comparing data in this report with data published in our 1996-1997 data report.

The two differences in the case definition are as follows:

1. The case definition now includes birth defects detected among induced pregnancy terminations before 20 weeks gestation. The registry has always collected information on birth defects among induced terminations before 20 weeks gestation in the facilities we access, but such records were called additional events (rather than cases) and they were not included in previous statistical reports.

2. The case definition now includes birth defects among fetal deaths before 20 weeks gestation. Prior to April 5, 2001, when the current case definition was adopted, the registry did not collect information on birth defects among fetal deaths before 20 weeks gestation.

Although the current case definition includes fetal deaths before 20 weeks gestation, most 1999 and much of 2000 surveillance activities were completed at the time the case definition went into effect. As a result, the 1999 and 2000 data in this report include only a very small number of fetal deaths before 20 weeks gestation.

Data in this report are not entirely comparable to data presented in some earlier reports because of the changes in case definition. Data from 1996 forward have been re-analyzed to include birth defects among induced pregnancy terminations before 20 weeks gestation, and these data are presented in Table 2. The data in Table 2 provide a more suitable comparison to 1999 and 2000 data in this report than 1996 and 1997 data previously published.

Data Collection

The Texas Birth Defects Monitoring Division uses active surveillance. This means it does not require reporting by hospitals or medical professionals. Instead, trained program staff members regularly visit medical facilities where they have the authority to review log books, hospital discharge lists, and other records. From this review, a list of potential cases is created. Program staff then review medical charts for each potential case identified. If the infant or fetus has a birth defect covered by the registry, detailed demographic and diagnostic information is abstracted. That information is entered into the computer and submitted for processing into the registry. Quality control procedures for finding cases, abstracting information, and coding defects help ensure completeness and accuracy.

Records in the birth defects registry were matched to birth certificates and fetal death certificates filed with the Texas Bureau of Vital Statistics. When a record in the birth defects registry matched a birth or fetal death certificate, and information was not missing from the matching certificate, the analysis for this report used demographic data from the birth or fetal death certificate for the following: date of delivery, sex of the infant or fetus, mother's date of birth, mother's race/ethnicity, and mother's county of residence at the time of delivery. When a registry record did not match a birth or fetal death certificate, or when information was missing from the certificate, then this report used demographic data abstracted from medical records. Regardless of the source of demographic information for this report, all diagnostic information was abstracted from medical records.

Data Analysis

Results are presented for 49 selected defects monitored in 1999 and 2000, regardless of whether the defect occurred alone or together with others. (See Appendix B for the BPA codes used to define the birth defects shown in this report and Appendix C for a glossary of birth defect terms.) Because an infant or fetus often has more than one defect, and not all monitored defects are included in these analyses, it is not meaningful to sum all diagnostic categories in the tables to obtain the total number of children with birth defects. In the data tables, totals are shown in the line labeled, "Infants and fetuses with any monitored birth defect."

Tables include the number of cases found, the estimated prevalence per 10,000 live births, and the 95% confidence interval for the prevalence. A case is an infant or fetus with the specified birth defect. Birth prevalence (also referred to as rate) was calculated as follows:

$$\frac{\text{Number of cases}}{\text{Total number of live births}} \times 10,000$$

The prevalence is only an estimate of the true prevalence, which is unknown. The 95% confidence interval contains the true prevalence of a birth defect 95% of the time. A wide interval indicates the uncertainty stemming from small numbers. This report displays 95% confidence intervals based on the Poisson distribution when there are 100 or fewer cases, and based on the normal distribution when there are more than 100 cases. Poisson regression was used to identify statistically significant differences in prevalence between groups, for example, between mothers of different ages, or between males and females.

Limitations of these Data

These data are subject to a few limitations. First of all, the registry only includes birth defects diagnosed within one year after delivery (except for fetal alcohol syndrome), so birth defects detected after the first birthday and diagnoses that are refined after the first birthday are not in the registry. Second, we miss diagnoses that are made outside of Texas or in Texas facilities that our staff does not access at this time, such as prenatal diagnostic facilities and private physicians' offices. Third, data are collected from medical records and as such are subject to differences in clinical practice.